THE REPUBLIC OF UGANDA

EPRC ECONOMIC POLICY RESEARCH CENTRE

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SOCIAL DYNAMICS AND LACK OF FAMILY SUPPORT: KEY BARRIERS HAMPERING THE ELIMINATION OF HIV/AIDS MOTHER TO CHILD TRANSMISSION

JULY 2016

POLICY BRIEF NO. 6/16

INTRODUCTION

In full compliance with the National Priority Action Plan (NPAP, 2013), between 2011 and 2013 Uganda registered a 65% reduction in new HIV infections among children. Moreover, between 2000 and 2012 the number of AIDS-related deaths among children aged 0-4 years decreased by more than half. Progress notwithstanding, with a national average of 18% of new HIV infections due to Mother To Child Transmission (MTCT), the elimination of Mother to Child Transmission (eMTCT) continues to face significant challenges.

According to a study by the International Organization on Migration (IOM, 2013), it is estimated that in Uganda approximately 130,000 people live in fishing communities where HIV infection rates are almost 3-4 times higher than the reported national average of 7.3% (UAIS, 2011). This study points to the high degree of mobility and lack of HIV/AIDS services as major factors contributing to high HIV prevalence rates. High rates of HIV infection in fishing communities have been identified as a severely compromising factor affecting national efforts to eliminate MTCT in Uganda.

Careful scrutiny of child and maternal health indicators vs. primary health care (PHC) releases reveals that in spite of relatively low PHC releases per capita, the Buganda sub-region accounts for an exorbitantly high coverage rate of HIV testing among children born to HIV positive mothers. On the basis that the central region is home to a disproportionately high number of fishing communities, the aim of this brief is to provide a better understanding of the factors hampering the elimination of MTCT, especially in fishing communities.

CASE STUDY: BUGANDA SUB-REGION

As it was stated at the outset, high rates of HIV infection in fishing communities represent a severely compromising factor hampering national efforts to eliminate MTCT in Uganda. Within the Buganda sub-region, the districts of Buikwe, Masaka, Mpigi, Mukono, Rakai and Wakiso border Lake Victoria, and 28 district sub-counties host a disproportionately high number of fishing communities.

In spite of relatively low PHC releases per capita (UGX 2,530), the Buganda sub-region reported coverage rate of HIV testing among children born to HIV positive mothers is as high as 153% (Figure 1). Whereas Buganda's exorbitantly high coverage rate stands as testament of the sub-region's ability to deliver effective HIV/AIDS services and attract communities from neighbouring regions to travel to urban centres for presumably higher quality of care, it is also symptomatic of stark inequalities between and within regions. To illustrate, the coverage rate of HIV testing among children born to HIV positive mothers in Wakiso and Mpigi districts stands at approximately 120% and 60%, respectively (Figure 2). The same figure shows clear signs of a widening disparity in the districts' ability to attend to the needs of their population.

Most alarmingly, however, Figure 3 shows that Mpigi's underperformance coincides with the receipt of the second highest FY 2010/11-2014/15 cumulative PHC per-capita release in the sub-region. To elaborate further, between FY 2010/11-2014/15, in spite of a cumulative PHC per-capita release double that of Wakiso, the rate of improvement in HIV testing among children born to HIV positive mothers in Mpigi (44.6%) was significantly lower than in Wakiso (104.7%).

Figure 1: HIV testing among children born to HIV positive women (%) vs PHC non-wage release (UGX) per capita (FY 2014/15)

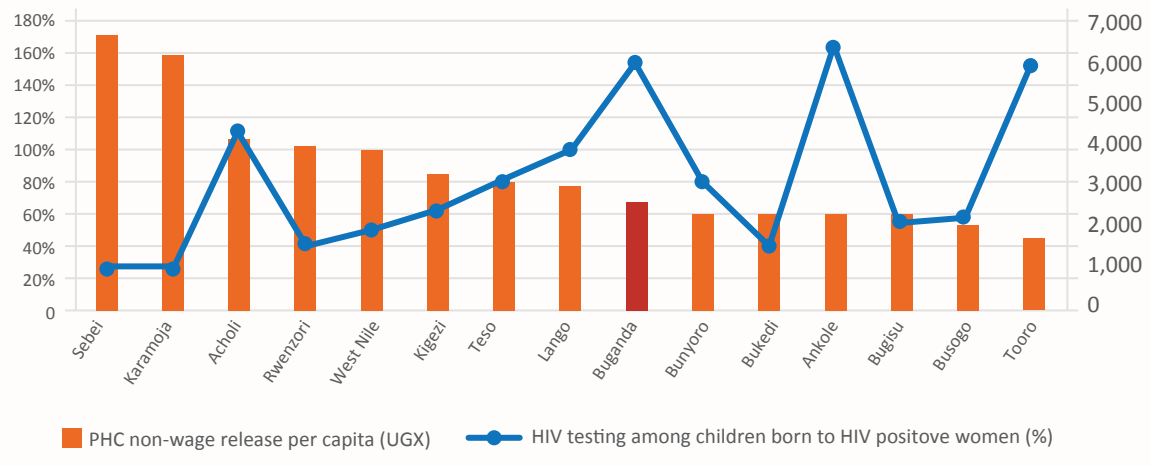


Figure 2: HIV testing among children born to HIV positive women (%)

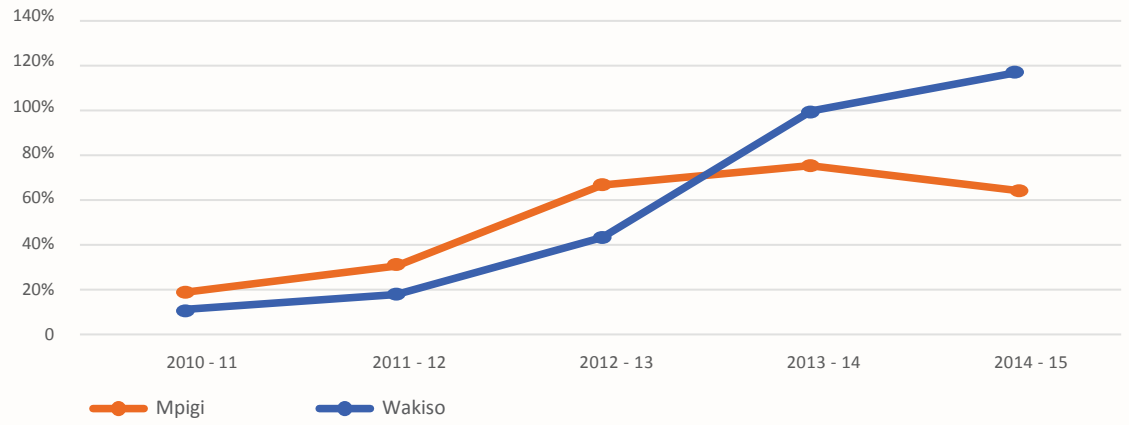
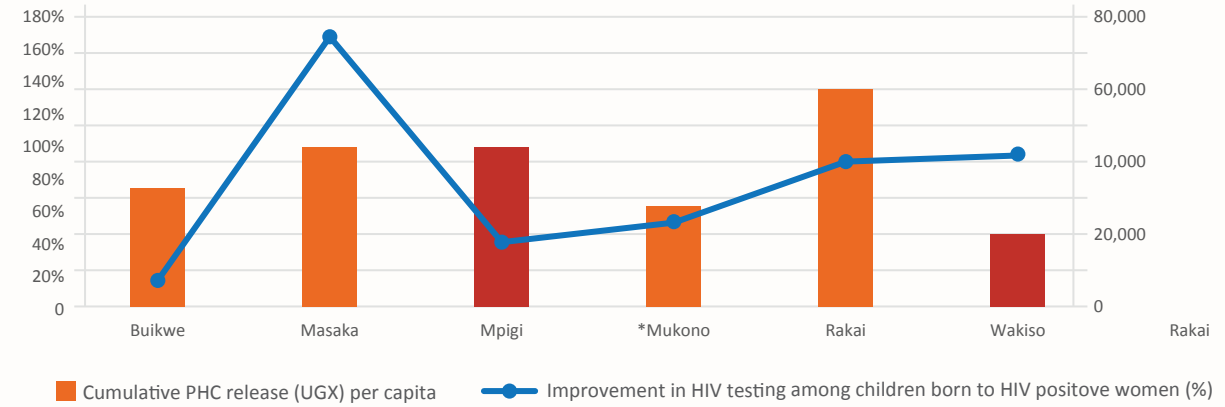


Figure 3: Improvement in HIV testing among children born to HIV positive women (%) vs. Cumulative PHC release (UGX) per capita (FY 2010/11 - 2014/15)



**Mukono district improvement in HIV testing among children born to HIV positive women (FY 2010/11- 2013/14)*

EVIDENCE FROM THE FIELD

Field work consisted of structured interviews, Focus Group Discussions (FGDs) and Key Informant Interviews (KIIs) with district health officers, healthcare providers, and beneficiaries in Wakiso and Mpigi districts. Evidence from the field suggests that beyond the availability of financial resources, cultural norms, knowledge and attitudes, as well as the quality of services and the active engagement of pregnant mothers and their partners are likely to play a fundamental role in Government's efforts to reduce HIV/AIDS prevalence and ensure the effective delivery of national eMTCT programmes.

According to several FGD and KII respondents, **social barriers** and **lack of family support** represent a significant hurdle hindering the effective delivery of eMTCT services, especially in fishing communities. Stigma regarding one's HIV status and the fear of disclosure and victimization has significantly affected mothers' uptake of eMTCT services. To illustrate, if a mother is found to be HIV positive she needs to first consult her husband before accepting to enroll on treatment. But due to fear of domestic violence and abandonment, mothers tend to delay or forego ARV treatment as well as starting their newborns on prophylaxis. Interview reports document that upon discovery of their HIV status, most mothers enter a state of shock and show clear signs of depression and denial. Health workers indicated that mothers who tend to delay or drop out of treatment are the ones whose babies tested (HIV) positive.

> **"My mother-in-law always asks why I go to the health facility every first Friday of the month (ART clinic day). What do I do then? Sometimes I am forced to choose another day other than the ART clinic day but she still presses to know why".**
>
> *HIV positive mother, Kamengo sub-county, Mpigi*

High mobility and **migrant labour** also pose a significant challenge. In particular, health facilities in proximity of landing sites and peri-urban areas struggle to retain clients. Community leaders and health providers associated *lost* clients with migrant workers mainly settled on islands and landing sites, who "do not stay for long". FGDs and KIIs also confirmed that some clients are opposed to the idea of being easily identified or "labelled" and tend to provide health workers with false addresses which makes it difficult to follow-up on adherence to treatment.

> **"A certain mother has lost two babies to HIV/AIDS because she doesn't want follow the advice given by the health worker. We have sent a peer mother and a counsellor but she has consistently refused to enroll on the ARVs".**
>
> *Midwife, Kigungu landing site, Entebbe*

More broadly, FGD and KII respondents pointed to **long distances to health facilities**, and **poor quality of health services** as major hurdles hindering the elimination of MTCT. Structured interviews with mothers revealed that long travel distances to oftentimes poorly equipped health facilities compromises access to eMTCT services, especially at the time of delivery. In Mpigi district, Senyondo landing site is over 6 kilometres away from Bunjako HCIII. Evidence from the field unveiled that this facility also serves Katenga island, which is approximately 8 kilometres from Senyondo, making the total distance a mother from Katenga has to travel to access eMTCT services approximately equal to 14 kilometres. This is well beyond Government's policy of providing access to health facilities within a 5 kilometre radius. As a direct result, mothers opt to visit and deliver with Traditional Birth Attendants (TBAs) within their communities rather than in health facilities.

This phenomenon continues to be accentuated by the fact that health centres tend to be understaffed with long queues and limited facilities such as lack of basic supplies, water or electricity. Understaffing, especially midwives in health centres, has significantly affected the successful delivery of Ante Natal Care (ANC) and eMTCT programmes. Limited numbers of healthcare workers, overwhelmed by high numbers of patients, are simply unable to provide adequate quality of services including counselling. Failure to provide adequate HIV counselling services to mothers continues to result in low uptake of the eMTCT services.

> **"I am the only midwife – to do the testing, counselling, antenatal services and also deliver babies. How can I be able to test and counsel the over 30 mothers who turn up for Antenatal Care (ANC) a day? As a result I just test them without counselling.**
>
> *Midwife, Buwama sub-county, Mpigi*

POLICY RECOMMENDATIONS

i. Remove social barriers

a. Local Governments to work with Village Health Teams (VHTs) and/or Community Development Workers (CDWs) to establish peer support schemes within fishing communities.

b. Ministry of Health (MoH) and Local Governments to involve cultural, community and religious leaders to remove stigma and encourage male involvement.

c. Local Governments to empower Beach Management Units (BMUs) to deliver HIV/AIDS sensitization campaigns in fishing communities.

ii. Provide suitable and accessible services

a. MoH to provide tailor-made HIV prevention, eMTCT, care and support services for fishing communities.

b. Local Governments to extend HIV prevention, care and support services through innovative partnerships and implementation strategies such as outreach or mobile HIV service outlets.

iii. Remove supply-side bottlenecks

a. MoH to fast track staffing reforms and ensure adequate quality standards through availability of basic supplies, water and electricity.

b. MoH to accredit more facilities (e.g. private clinics) to provide eMTCT services. This measure could also be explored to include HCIIs.

c. Local Governments to empower VHTs to administer and distribute ARVs.

FOR ADDITIONAL INFORMATION:
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